

THE 2000 HIV/AIDS CARE AND PREVENTION COLLABORATION PROJECT

Background:

King County has a national reputation for its successful HIV/AIDS care and prevention system. As the demographics of the HIV epidemic continue to change and local data show increasing STD and HIV co-infection rates among men who have sex with men (MSM), local providers and planners sensed a need to increase collaboration between HIV/AIDS prevention and care systems. Thus, the Ryan White Title I HIV/AIDS Planning Council (“the Council”) in Seattle undertook a care and prevention collaboration needs assessment in the first quarter of 2000. The assessment, called the “Collaboration Project,” was jointly conducted by the Council and Public Health – Seattle & King County, the Ryan White Title I grantee.

The project aimed to see if care service providers discuss sex and drug use risk reduction with their HIV+ clients, and make appropriate referrals for clients whom they determine have ongoing risk reduction needs. The project also examined whether prevention workers who encounter HIV+ individuals in their work appropriately refer these clients into the care service delivery system. The project explored whether referrals were happening across systems, whether those referrals were effective, and what barriers stood in the way of effective referrals. Once barriers to cross-system referrals were identified, the final project goal was to determine what changes can be made, to improve the resource linkage and referral capacity for each of these HIV/AIDS systems.

Methods:

The Council convened a Collaboration Work Group including members of both the care and prevention sides of the Council, including persons living with HIV/AIDS, to develop and oversee the project. The assessment consisted of a series of one-on-one phone or in-person interviews with providers from the prevention and care systems, and follow-up focus groups with care and prevention interview subjects and HIV+ consumers to construct solutions to barriers and problems identified in the interview process.

Two staff members of the PHSKC HIV/AIDS Program conducted the interviews, along with two contract interviewers, one familiar with HIV care programs, and one familiar with the prevention field. The Council sought to interview 102 providers, from the spectrum of care services; 74 interviews were actually conducted (72.5% of target), and also sought to interview 46 prevention providers; 31 prevention provider interviews were completed (67.3%). Interviews conducted during January and February 2000 took about 20-25 minutes each.

Results of Provider Interviews:

Demographic data revealed notable differences in the populations of care and prevention providers, and the ways in which services are delivered: Provider Gender: Care service providers were twice as likely to be female than prevention providers (53% versus 26%). Provider Race/ethnicity: Prevention providers are much more racially diverse than those in the care system. Over half of the prevention providers interviewed identified as non-white (48% Caucasian, 26% Latino/a, 13% American Indian or Alaska Native, 10%

Asian/Pacific Islander and 10% African American). In contrast, 82% percent of the care providers interviewed were Caucasian, with far smaller numbers of persons of color (4% Asian/Pacific Islander, 3% Latino/a, 1% African-American and 1% American Indian/Alaska Native). Thus, the care provider population is fairly similar to the demographics of King County as a whole, while the demographics of the prevention system are more representative of the epidemic trends in populations at risk for HIV. This suggests that clients being referred into the care system by prevention workers are less likely to encounter providers from their ethnic and cultural backgrounds.

Populations served: Unlike care service providers, all prevention providers focus activities on specific target populations. The most frequently targeted populations were MSM (61%), communities of color (35%), and injection drug users (IDU, 19%), with smaller numbers of providers targeting women, youth and adolescents, and HIV+ individuals. In contrast, 68% of care providers stated that they do not work with a specific target population, instead offering services to all eligible clients.

Job focus: Prevention providers are much more likely than care service providers to engage in more than one form of service provision. Half (48%) of the prevention providers interviewed engaged in multiple activities (e.g., doing outreach and giving presentations or performing both individual and group level counseling.) Only 8% of care service providers reported performing multiple activities, instead focusing on specific job functions (e.g., case management, primary medical care, mental health therapy, peer counseling, substance use treatment and counseling, etc.).

Previous history of service delivery: Forty-two percent of prevention providers interviewed had previously worked in the care service arena, while only 11% of care providers had previously performed prevention activities. This suggests that prevention workers may be more likely to know about care services (e.g., types of programs, methods, expected outcomes) than care workers are to know about prevention services.

Referral Capacity between Systems:

We asked prevention providers if they had offered any referrals to medical care or other services in the past year, defining a “referral” as giving a client the name and/or phone number of a *specific provider or provider agency*, rather than just suggesting that the individual needed care. Ninety percent of the prevention providers interviewed said that they had made a care referral in the past year. (The 10% who had not were providers who stated that none of their clients reveal their HIV status.)

The most common referral was for medical care; about 70% of providers made specific medical care referrals. Sixty-one percent of respondents made case management referrals, 50% made referrals for housing assistance, 46% referred clients for mental health therapy, and 46% made referrals for substance use treatment. Smaller numbers made referrals to emotional support programs (21%), insurance programs (21%), complementary therapies (14%), food and meal programs (11%), and various other services. Eleven other services were mentioned once or twice.

To find out if prevention providers who make referrals are referring their clients to the appropriate programs, the interview asked “Where would you refer clients for each of the following services?” Providers were instructed to name as many service providers within each category as they knew. In general, referral sources were most appropriate in the areas of HIV counseling and testing, medical care, and case management. Prevention workers were less likely to identify available mental health and substance use resources. Of particular concern was the limited awareness prevention workers had about referrals to medical insurance programs (such as the Early Intervention Insurance Program and the Evergreen Insurance Program) and Washington State’s AIDS Prescription Drug Program.

Care providers were less likely to have made referrals for clients into prevention/risk reduction programs than prevention providers were to have made referrals into care. While 90% of prevention providers had made referrals into the care system, only 43% of care providers referred clients into sexual risk reduction services. Many fewer volunteers (7%) than paid staff (51%) made risk reduction referrals.

Most of the sexual risk reduction referrals made by care providers seemed to be appropriate. The majority were to programs targeting gay/lesbian/bisexual/ transgender (GLBT) individuals. Providers who were asked follow-up questions about the specific programs or methods offered by these agencies were relatively unaware of the specific nature of the programs to which they were referring. Care providers seemed to need as much information about prevention programs as prevention providers needed about care service referrals.

Two-thirds (66%) of care providers referred a client during the past year to a program that addressed drug use risk reduction. Seventy-eight percent of paid staff had made such a referral, versus 14% of the volunteers. Similar to referrals for sexual risk reduction, the largest number of referrals for substance use treatment and counseling were made to agencies targeting the GLBT population.

Barriers to Inter-System Collaboration:

We asked prevention workers about the barriers they encountered in making referrals to care services. Cultural and language barriers were a main concern, particularly for providers targeting clients of color (23%). When prevention workers refer clients into the care system, these clients may encounter providers who neither speak their language nor understand their cultural backgrounds. Nineteen percent of the interview subjects said that needed services were not available. This may represent a lack of information, since the King County care continuum is fairly comprehensive and prevention providers might be unaware that services are actually available. Nineteen percent stated that they did not know where to make appropriate referrals, and 16% expressed concerns about client confidentiality.

Focus group participants offered several suggestions about improving the relationship between prevention and care providers. They urged care and prevention providers to conduct presentations at each other’s agencies to establish resource linkages. Prevention

providers also wanted to see care service agencies make a commitment to changing their staffing patterns to increase diversity, which means paying increased attention to recruitment, hiring and training.

Some prevention providers were very concerned about “handing off” clients to the care service continuum. Despite lengthy up-front work to actually get a client into the care system, once that client enters the care system the prevention worker may no longer be seen as a valuable resource. When the prevention provider has established a relationship with the client, these prevention providers suggested that the care provider (including the client’s case manager) consider the prevention provider as part of the client’s immediate support system and involve the prevention provider in client consults.

When care service providers were asked about barriers they faced in making referrals to HIV risk reduction programs, over a third (38%) lacked information about available programs. They lacked knowledge about specific agencies to which referrals could be made, as well as lack of familiarity with the kinds of programs offered by these agencies. Nineteen percent of care providers said their clients were resistant to or not interested in risk reduction programs. Care providers interviewed and in focus groups expressed desire for in-service training offered by prevention agencies, particularly inter-agency presentations between care and prevention providers. This kind of approach would allow them to become familiar with other agencies’ staffs, identify key resource persons to whom they could make referrals, and learn about the range of prevention programs.

Care Providers’ Discussion of Sexual and Drug Use Issues with Clients: Asked about discussing sexual risk reduction, a quarter (26%) said they discuss sexual risk reduction with all their clients. Eight percent said they never discuss risk reduction with any clients, while 23% said they discuss it with less than one-quarter of their clients. An important distinction was that 66% of paid staff discussed sexual risk reduction with at least half of their clients, versus only 36% of volunteers.

Smaller numbers of care providers reported inquiring about STD risks from their clients. Only 18% ask all clients about risk behaviors related to STD transmission, and 11% discuss STD risk reduction with clients. Some providers stated that since they already have this information in the client’s chart, they did not re-initiate a discussion. However, it is unclear if these providers continued to discuss ongoing risk potential with their clients. Again, most (59%) paid staff discussed STD risk reduction with clients, versus only 14% of volunteers.

Barriers to offering clients sexual risk reduction messages that providers mentioned most were client-, rather than provider-related. The largest barrier identified was perceived client discomfort in talking about sex, mentioned by 35% of providers. Sixteen percent mentioned that clients’ might perceive personal guilt or shame discussing sexual behaviors. Fifteen percent believed that male clients might feel uncomfortable talking to female providers about sexual issues. An additional 15% of providers, mostly volunteers, said that discussing sexual behaviors and risk reduction with clients was not part of their job.

A much higher percentage of care providers discuss drug using behaviors and risk reduction with their clients. Nearly half (47%) initiated discussion about drug related behaviors with all clients. Only 15% never initiated discussion about drug use behaviors. Again, 56% of paid staff inquired about drug use from all of their clients versus only 7% of volunteers.

To questions about barriers to discussing drug use related risks and what might help overcome these barriers, most barriers mentioned were client-related, including clients' denial of drug use (identified by 23% of providers), clients' fear of being judged or of reprisals being levied against them (23%), general resistance to talking about this topic (22%), and shame about using drugs (19%). Only 8% of providers identified personal barriers, in this case their own negative attitudes towards drug use and IDU.

Two follow-up focus groups interviewed twenty-three care providers, including 13 females and ten males, all of whom were white. Participants wanted sexual and drug use behavior and risk reduction discussions formalized into their jobs, with questions on these topics included in all initial client assessments and periodic re-assessments. They also wanted to see provider trainings around various sexual counseling issues. Care providers also wanted more training on substance use issues and increased linkages between the HIV and substance use systems.

Consumer focus groups:

Project staff followed up the prevention and care provider focus groups with two focus groups of HIV+ consumers to expand on issues brought up by providers, and to see if consumers could offer additional solutions to the problems identified in provider interviews. A total of 22 consumers attended the groups, including 17 males and five females. At least ten of the participants were persons of color.

To feel comfortable discussing sexual risk behaviors, focus group participants reiterated the need for trust to be developed between providers and clients. There was unanimous agreement among focus group participants that it was always appropriate for medical care providers to bring up these issues, since they felt that confidentiality was guaranteed in the medical setting. If consumers understood that medical providers routinely inquired about these issues with patients, no one would feel singled out.

Consumers felt it was only acceptable for case managers to discuss sexual and drug use risk reduction issues with clients if trust had been established. They felt it was very important for case managers to explain how and where this information would be used. Some clients expressed concerns that revealing unsafe sexual behaviors to non-medical providers, such as case managers and mental health therapists, would lead to providers "policing" their clients. This discussion evoked confidentiality and privacy concerns brought up in Washington State around the recent implementation of named reporting of HIV positive persons.

Consumers expressed mixed sentiments regarding the appropriateness of discussing sexual and drug use risk reduction with other types of providers. Most felt it was suitable for mental health providers to discuss sexual and drug use issues if the client brings it up, but were concerned that mental health professionals might be judgmental about client behaviors. Clients felt it was important for substance use counselors to address all types of drug use risk reduction, but felt it was only appropriate for substance use counselors to ask about sexual risk behaviors as they related to the client's alcohol and drug use. Participants felt it was important for peer counselors to be knowledgeable about these issues, particularly when the client brings them up.

Summary:

This needs assessment taught the Planning Council and PHSKC much about the current nature of the care and prevention systems, and their overlap. The study identified successes in the current inter-system resource and referral processes, and highlighted collaboration and communication gaps between the two systems. The project also identified concrete suggestions about how the entire continuum of HIV prevention and care services might work collaboratively to make improvements.

Given increasing national evidence of complacency about sexual risks and local data that many MSM with STD also carry HIV, the fact that so few care providers discuss these risk issues is a great concern. With evidence on the relationship between STD prevention and HIV prevention, as well as the possibility of re-infection and illness progression, it is increasingly important for providers to discuss sexual risks with their clients in an ongoing fashion – an area to address in care provider training.

Based on the findings of the Collaboration Project, the Council has implemented several changes in the King County prevention and care continuum of service delivery in the upcoming year. These include:

- Reserving \$65,000 in Ryan White Title I funding to train care providers on how to more effectively address sexual and drug use risk reduction with clients;
- Attaching caveats to FY2001 funding in the Ryan White service categories of ambulatory care and substance use, to ensure that favorable consideration will be given to proposals which demonstrate strategies to train staff to assess risk reduction issues and successfully incorporate counseling and/or referral and follow-up for prevention services;
- Using CDC funds to develop and implement prevention case management programs at the Harborview Madison Clinic and Northwest AIDS Foundation, to help HIV+ clients who need and want further risk-reduction counseling and assistance, and
- Assigning ongoing committee status to the Collaboration Work Group (now called the Collaboration Committee), to ensure that care/prevention collaboration and coordination issues are a continuing topic of discussion for the entire Council.

We recommend that other municipalities and care and prevention planning groups consider undertaking a similar process in their community.

For more information about the Collaboration Project, please contact Jeff Natter at (206) 205-5506.

Submitted by Jeff Natter, MPH, Theresa Fiano, Barb Gamble, MPA and Bob Wood, MD.